

DNA Fingerprinting and Ethics

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In this time of constant changes in science and technology, there are many issues that remain controversial. The issue of DNA fingerprinting and database systems are of great importance. When the double-helix shape of the DNA molecule was first discovered and introduced by James Watson and Francis Crick, it opened the door for extensive research. From the DNA model to the process of "gel electrophoresis" that was developed by Sir Alec Jeffrey, the use of genetic technology has advanced beyond the awareness of most of the general public.

The ability to extract DNA from skin, blood, hair, or any part of living or once-living tissue has made this type of technology important. The use of DNA fingerprinting is used to determine the innocence or guilt of an accused person in the court of law. The use of DNA fingerprinting is also used in determining parental rights and responsibilities.

Along with DNA Fingerprinting this unit will address the issue of privacy relating to one's DNA sample. The use of large database systems which can hold the genetic history of an individual, and the security of these systems and the information they hold are of great concern. There are many legal, social, and ethical issues attached to these database systems which are in use in many countries.

Students will be introduced to the basic knowledge of the DNA molecule, its shape, what information it holds, its function, and how it divides during mitosis. Students will report on the works of Rosalind Franklin, who that greatly assisted the work of James Watson and Francis Crick. Students will also report on the work of Watson and Crick and their discovery of the double-helix shaped DNA molecule. Students will be responsible for building a model of the DNA molecule. Students will also report on the work of Sir Alec Jeffery, a geneticist from England. They will need to know and understand the process of "gel electrophoresis" which is the separation of DNA material. Students will need to be able to put the process into concept map form. Continued work by the students will require them to report on published material that cover the areas of DNA database systems and security, privacy issues, and legal/law issues. Students will report on published paternity cases in which DNA fingerprinting was used. Finally, students will be reporting on a personal level regarding the possibility of their own DNA being used in obtaining employment, or

insurance, and any other possible situations where they might be expected to give a sample of their own DNA for testing and database storage. Information for these reports will be available from the internet and previously published reports.

Academic Setting

Taft Middle School is located in the North Valley at 620 Schulte Rd. NW. Taft is one of twenty-six middle schools in the Albuquerque Public School system. Taft is in the North Valley cluster along with Garfield Middle School and Taylor Middle School. Taft, Garfield, and Taylor Middle School all feed into Valley High School.

Taft is one of the smaller middle schools in Albuquerque. Its student population is a mixture of Hispanic, Anglo, Native American, African American, and Asian. Taft also is home to a progressive side-by-side program for handicapped students. The enrollment of Taft is over 600 students, which is beneficial to the learning environment.

Rosalind Franklin, British Chemist (1920-1962)

Deoxyribonucleic acid, or DNA, carries inherited information in the genes of most living things. In the early 1950s, scientists realized that the key to finding out how this information was stored and reproduced lay in the complex structure of DNA.

Rosalind Franklin took x-ray photographs that gave two rival scientists, James Watson and Francis Crick, the clues they needed to work out the structure of DNA. Rosalind Franklin was born on July 25, 1920, in London. Rosalind decided at age 15 that she wanted to be a scientist. Her father objected, believing like many other people of the time that higher education and careers made women unhappy, but she finally overcame his resistance. She studied chemistry at Newnham, a women's college at Cambridge University, and graduated in 1941 (Sayer 69).

As a way of helping her country during World War II, Franklin became assistant research officer at the Coal Utilization Research Association (CURA). She did research on the structure of carbon molecules, bringing order into a field which had been previously in chaos. She turned some of this work into the thesis for her Ph.D., which she earned from Cambridge in 1945. Seeking new challenges, Franklin went to work for the French government's central chemical research laboratory in 1947. She also learned a technique called x-ray crystallography, to which she would devote the rest of her career.

Many solid materials form crystals in which molecules are arranged in regular patterns. In 1912 a German scientist named Max von Laue

found that if a beam of x-rays is shone through a crystal, some of the rays bounce off of the crystal's atoms, while others pass straight through. When photographic film, which is sensitive to x-rays, is placed on the far side of the crystal, the resulting photograph shows a pattern of black dots that can reveal important facts about the three dimensional structure of the molecules in the crystal (Sayer 69).

Chemists eventually also found ways to use x-ray crystallography on amorphous compounds, which did not form obvious crystals. Most of the complex chemicals in the bodies of living things are amorphous compounds. Molecular biologists were beginning to realize that the structure of these compounds revealed much about their function, and crystallography was a promising tool for revealing that structure. One of the molecules the structure of which scientists were most curious about was DNA, which is found in every cell of the body and had been shown in the late 1940s to be a carrier of inherited information. Franklin became expert at taking x-ray photos of amorphous compounds, and she was eager to try her skill on biological molecules. In 1950 she joined a group of researchers at Kings College at the University of London who were trying to work out the structure of DNA.

Scientists knew that the DNA molecule consisted of several smaller molecules. It had a long chain, or "backbone," made of alternating molecules of sugar and phosphate (a phosphorous-containing compound). Four different kinds of other molecules called bases were attached to the backbone. No one knew, however, whether the chain was straight or twisted, how the bases were arranged on it, or how many chains were in each molecule. Franklin hoped that the x-ray photographs would provide this information.

Franklin photographed two forms of DNA, a "dry," or crystalline form and a "wet" form that contained extra water molecules. No one had photographed the wet form before. At the time, Franklin was not sure which type gave the more useful information. She took an excellent photograph of the wet form in May 1952, but she put it aside in a drawer and continued working with the dry form.

Franklin believed that there was more than one chain in each DNA molecule, and that at least in the wet form each chain had the twisted shape of a helix, like the threads of a screw. She also believed that the phosphate backbone was on the outside of the chain and the bases on the inside. She did not follow up on these ideas, however. Some of her friends think she could have, and discovered the structure of DNA herself, if she had a scientist of her own caliber with whom to talk over ideas. Aaron Klug, who worked with her later wrote: "She

needed a collaborator,somebody to break the pattern of her thinking, to show her what was right in front of her, to push her up and over."(Sayer 70).

Two Cambridge scientists, a young American named James Watson and a Brit

named Francis Crick, were also trying to work out the structure of DNA. Although Watson saw himself and Crick as competitors of the King's College group, he and

another scientist named Maurice Wilkins became friends. On January 30, 1953, he visited Wilkins at King's College. Without asking Franklins permission, Wilkins showed Watson the photograph of "wet" DNA which Franklin made in May 1952. When Watson saw the photograph, he wrote later, "my mouth fell open and my pulse began to race." He hurried back to Cambridge to describe the photo to Crick (Sayer 70).

To Watson, the x-shaped pattern of dots in Franklin's photo showed clearly that the DNA molecule had the shape of a helix. On the basis of this and other evidence, he and Crick concluded (by this time Franklin also had) that the molecule consisted of two helices twined around each other. The backbones were on the outside and the bases stretched across the center. In other words, the molecule was shaped like a spiral staircase or a twisted ladder with the bases as steps or rungs.

After further discussion, Watson and Crick had two key insights that went beyond the evidence in Franklin's photo. Two of the four kinds of bases were larger than the other two, and Watson realized that one large base plus one small one made a pair exactly the right size to fit in the space between the backbones indicated in Franklin's photograph. Crick, in turn, realized that the two backbones coiled in opposite directions, so the molecule looked the same from either end.

Watson and Crick published a groundbreaking paper on the structure of DNA in Britain's chief science journal, *Nature*, on April 25, 1953. Neither then nor later did they fully credit Franklin for the important part her photograph had played in their discovery, and Franklin herself probably never realized its role. By the time the Cambridge scientists' paper appeared, she was no longer working on DNA. She moved from King's College to Birkbeck, another college in the University of London, and was beginning an x-ray study of a common plant virus called tobacco mosaic virus. Almost nothing was known about the structure of viruses at that time. Franklin drew on her crystallography studies to make a model of the tobacco mosaic virus

which was exhibited at the 1957 World's Fair in Brussels.

In 1956, Rosalind Franklin discovered that she had ovarian cancer. The cancer proved untreatable, and she died on April 16, 1958. Four years later, Watson, Crick, and Wilkins shared the 1962 Nobel prize in physiology or medicine for their work on DNA. Nobel Prizes are never awarded after a person's death, so there was no question of including Franklin. Supporters and critics still debate whether she would or should have been included if she had lived. As it was, she was remembered through the high praise of some of her colleagues.

James Watson and Francis Crick

James Watson and Francis Crick were key figures in the race to find the geometric structure of DNA. Essentially, three laboratories were involved in the race, two in England and one in the United States. In England there was the Cavendish Laboratory at the University of Cambridge, where Crick and Watson won the very close race. Also involved was the Laboratory at King's College, London, where Maurice Wilkins and his associate Rosalind Franklin were working on DNA. And in the United States, Linus Pauling in his laboratory at the California Institute of Technology, was trying to win the race that certainly would yield one or more Nobel Prizes. (Pauling already had won two Nobel Prizes.)

Much progress was made in the study of genetics during the twentieth century, and especially during the 1940s and 1950s. Thus the stage was set for the major discovery of James Watson and Francis Crick. Watson was born in Chicago in 1928. He graduated from the University of Chicago at age nineteen, and received his doctorate at Indiana University at the age of twenty-two. He then received a postdoctoral fellowship to study the biochemistry of DNA in Copenhagen. In August 1951 he obtained a fellowship to work in the University of Cambridge's eminent Cavendish Laboratory. Originally Watson was assigned to work in the laboratory of Max Perutz and John Kendrew, but once he met Francis Crick, they were destined to work together (Curtis 251).

Francis Crick was born at Northampton, England, in 1916 and was educated at University College, London. His first interest was physics. During World War II he was involved in radar research and also did some excellent work on magnetic mine development. When Watson arrived at the Cavendish Laboratory, Crick was thirty-five years old and almost unheard of. It was when Crick and Watson realized that DNA was vital to the interests of both that the inevitability of their collaboration became a fact.

The director of the Cavendish was Sir Lawrence Bragg, one of the founders of crystallography, and a Nobel Prize winner who, for forty years, had been following and solving x-ray diffraction structural puzzles. Sir Lawrence's concern was the fact that over a twenty-five year period, Linus Pauling of the California Institute of Technology had often beaten the English labs to the punch. He had won almost every scientific race to date, and Bragg wanted his laboratory to be the first to determine the structure of DNA. This discovery would prove to be one of the most important scientific breakthroughs of all time. Although at first forbidding Crick to work on DNA, Sir Lawrence eventually decided not to impede the research of the team of Crick and Watson (Curtis 251).

From the fall of 1951, when Watson arrived at the Cavendish, until April 1953 there were repeated highs and lows in the research. Both Watson and Crick had decided that, in light of Pauling's helix protein structure, the likeliest structure of DNA would also prove to be helical - a single, double, or triple chain. Compounds called bases, since they were known to exist in the DNA molecule, might extend outward at right angles to the chain or chains. Rosalind Franklin, whose x-ray diffraction photograph of crystalline DNA was the clearest, never believed that the structure was even a helix, let alone a double helix. She did, however, correctly insist that the probably straight chain or chains were comprised of alternating sugar and phosphate molecules.

The actual structure built by Watson and Crick was a double helix. It can be compared to a twisted ladder or to a spiral staircase. The rails of the ladder are the two chains, and the rungs are the combinations of the four bases, adenine (A) and thymine (T), cytosine (C) and guanine (G). It turned out that these rungs didn't extend outward, they were connected to the twisted rails of the mythical ladder. But it was the spiral staircase analogy that appealed to Watson. In 1952, while working on the structure of the tobacco mosaic virus, he spent a weekend at Oxford. Every helical staircase he saw that weekend made him more confident that other biological structures would also have helical symmetry. The steps of this staircase would be as a twisted ladder, would be paired bases, and the banisters would have the sugar and phosphate chains.

Finally, it was James Watson who became obsessed with making the model, initially playing with cardboard cutouts. Pauling had said that models were needed to find out "which atoms like to sit next to each other." (Curtis 255). Watson and Crick had come to realize that two sets of paired bases could form the rungs of the ladder. Adenine and guanine are double-ringed structures called purines. Thus the correct bonding of each rung was like to unlike (purine to pyrimidine),

and the rungs connected at right angles to the backbone of the structure, the twin helical chains. Watson had a false start but was set straight by Jerry Donohue, an American crystallographer; he correctly showed how the hydrogen atoms that bonded the bases could shift position. Now it worked!(Curtis 255). A machine shop manufactured the parts - flat metallic bases and the twin helices of altering sugar and phosphate molecules. After days of intensive playing with the structural elements, the investigators connected all the pieces the right way and the model was complete. Very important to the process was that the connections be stereochemically correct. The model also had to satisfy the x-ray data.

As soon as the model was complete, everyone came to see it. Bragg had his first look late in the morning of the day the model was produced. He was satisfied but wanted the chemist Alexander Todd to check the model's accuracy. Watson and Crick agreed.

Everyone was gracious about Watson and Crick's success. Maurice Wilkins, even though he had lost the race, was excited (in Watson's words), "that the structure would prove of great value to biology." Fortunately he shared in the Nobel Prize. Instead of reacting with the hostility her fellow workers expected, Rosalind Franklin showed genuine delight. Her beautiful x-ray photographs had convinced Watson and Crick (although not herself) that the structure was a double helix and had proved that the two helices, (the backbones), were located on the outside of the molecule. Franklin had always maintained that the sugarphosphate backbone would be located on the outside.

The Genome Project is under way to map and sequence all human genes. This project should make major contributions to human health . DNA "fingerprints" are now in use in the courts as evidence to exonerate innocent people and to convict the guilty. Through a complex process DNA from the blood, semen, flesh, and other parts of an individual can identify that person as unique. When Watson and Crick built their model, they knew that important scientific advances would result from their work. It is clear that their dreams of the future are coming true each day with increasing frequency.

Alec Jeffrey

In 1984 Alec Jeffreys, a geneticist at the University of Leicester in England, was studying the evolution of genes. He had become interested in a genetic peculiarity known as the "intron." Not every base in a chromosome is part of a gene. Some sequences of bases are "nonsense" sequences, with no obvious meaning. They are not genetic recipes but more like marginal scribbles, parts of the genetic library

that do not appear to contain genetic instructions. These meaningless sequences are referred to as introns. The more meaningful sequences of bases that make up the genes are sometimes known as exons. Introns can occur at any point on a chromosome, even right in the middle of a gene. When the genetic recipes are copied to RNA molecules prior to being converted into proteins, the intron sequences are snipped out by special "editor" enzymes (Lampton 33).

Why do introns exist at all? Some scientists believe that they are an important part of the evolutionary process. It is possible that introns represent genes that were useful long ago in our distant ancestors, but that are no longer needed. Jeffreys noticed an odd characteristic of introns. They are often made up of the same sequence of bases repeated over and over again. But the number of repetitions varies from individual to individual. In one person, a particular sequence of bases may be repeated five times, while in another person it may be repeated fifty times. Why this should be the case, Jeffreys did not know. It occurred to him that this might be a useful way of distinguishing one person's genes from another. The method by which he would do this hinged on the fact that molecules can be manipulated electrically.

The extremely tiny particles of which atoms and molecules are made have a special property known as electric charge, which comes in two varieties: positive and negative. If a molecule is made of equal amounts of negatively and positively charged particles, it will have no electric charge itself, because the electric charges of the particles of which it is made precisely canceled out. But if a molecule contains more positively charged particles than negatively charged, or vice versa, then the entire molecule will take on the same charge. And if there is an excess of positively charged particles, the molecule will have a positive charge.

DNA molecules have an excess of negatively charged particles, so the DNA molecules themselves have a negative charge. For years, scientists have taken advantage of this fact with a process called "gel electrophoresis," which uses electrical charge to sort pieces of DNA molecules according to size. In gel electrophoresis, a plate containing a substance known as "agarose" is placed between two electrodes, one of them negatively charged and one of them positively charged. The surface of the plate is divided up into a series of lanes, running from the negatively charged side to the positively charged side. At the negatively charged end of each lane is a small well into which is placed a small sample of DNA molecules. When the current is turned on, the negatively charged DNA molecules are repelled by the negatively charged electrode (because like charges repel) and attracted

by the positively charged electrode (opposite charges attract). As a result, the DNA molecules begin moving out of the wells and toward the positively charged electrode. But the DNA molecules are not free to fly across the plate and attach themselves to the positively charged electrode. To the DNA, agarose on the plate is like a dense molecular thicket through which the DNA molecules can move only with difficulty. Smaller DNA molecules can move through the agarose more easily, because they can slide between the agarose molecules. But larger DNA molecules quickly become mired in the agarose and barely move at all. When the current is turned off, the DNA molecules are distributed up and down the lane according to size, with the smallest molecules at the end of the lane nearest the positively charged electrode, the largest molecules at the end of the lane nearest the negatively charged electrode, and the in-between sized molecules somewhere in the middle (Lampton 37).

What Jeffreys was trying to do was count the number of repeating intron sequences in a fragment of DNA. Jeffreys used restriction enzymes to slice specific introns out of a DNA molecule. He then placed the sliced DNA in a well at one end of a gel electrophoresis plate and turned on the current to the electrodes. The DNA fragments began moving down the lanes toward the other end of the plate. He then turned off the electrodes and placed a sheet of nylon on the gel, letting the DNA molecules soak into the nylon like ink onto a blotter. Once the DNA was transferred to the nylon sheet, he exposed it to radioactive probes. A radioactive probe is a molecule that is specifically designed to attach itself to a specific sequence of DNA bases, in this case the bases of the specific DNA fragments that Jeffreys was examining. The radioactive probes tagged the desired sequences while ignoring the others allowing Jeffreys to examine the desired sequences. Jeffreys then placed the nylon sheet against a photographic plate and left it there long enough for the plate to become exposed to radiation from the radioactive probes. When he removed and developed the plate, he had a "photograph" of the positions of the DNA fragments on the sheet. This photograph shows the lanes in the plate overlaid with a series of dark stripes/bands representing the strips of radioactively tagged DNA fragments lying along the lane, with several lanes that can be used for comparison. Since the number of repetitions is different for different individuals, the pattern of dark bands will also be different for each individual. These dark bands, which are almost invariably compared to the bar codes found on packages in stores, are the "DNA FINGERPRINTS." (Lampton 38).

How unique are these fingerprints? Well, say that a specific pattern of

repeating sequences in a particular intron is shared by only ten percent of the people in the world. That means that the band on the DNA fingerprint can be used to determine if the person who contributed the DNA in one lane of the print is in the same ten percent of the population as the person who contributed the DNA in the other lane. By adding more and more fragments (and more and more bands) to the DNA fingerprint, we make the fingerprint more and more unique. If we use ten different fragments and the bands from all ten fragments match, then they were almost certainly contributed by the same individual, since the chance of two different people having the same pattern of bands is 1 in 10,000,000,000. The chance of two individuals having one band in common is 1 in 10.

When Jeffreys invented this technique, he immediately saw a number of possibilities inherent in it. Not only could it be used to identify criminals through DNA analysis of blood or hair or semen left at the crime scene, but it could be used to establish relationships between parents and children. With Jeffreys' process, it is possible to show genetic relationships between individuals by comparing their DNA fingerprints. Although no two individuals have the same genetic makeup or the same genetic fingerprints, the fingerprints of relatives should show distinct similarities and these similarities could be used as proof of the relationship. To see if the technique worked as he believed it would, Jeffreys tried his DNA fingerprinting technique on the members of a British family and carefully compared their fingerprints. To his delight, common gene patterns ran through all of the fingerprints, just as theory had indicated they should. Jeffreys was thrilled. The technique worked! Aware that the technique had distinct commercial possibilities, Jeffreys licensed it to a company called Imperial Chemical Industries and began performing DNA fingerprinting for a fee (Lampton 44).

Genetic Database Systems

The Rand Corporation's 1999 *Handbook of Human Tissue Sources*, estimated that more than 307 million tissue specimens from more than 178 million cases are stored and accumulated at a rate of more than 20 million per year. So the database is growing. But costs are prohibitive and logistics daunting. Then there is politics, which may be the ultimate barrier to the creation of a comprehensive national DNA database.

The *Genetic Privacy Act*, written as a proposal for federal legislation, stipulates donors' written authorization to collect or analyze DNA samples. While several states have adapted portions of the act for DNA privacy laws, there's no federal law regulating the growing

collection of samples. Barry Steinhardt, associate director of the ACLU, said not only would there be public resistance to a national DNA database, there is the "frightening prospect" that it would lead to genetic discrimination.(www.wired.com).

Dr. Mark Dantzker, associate professor of criminal justice at the University of Texas Pan American, compares DNA database systems to the police fingerprinting systems used. "We have available the ability to take everybody's fingerprint in the country and put that on file," he said. "Yet, the logistics of doing that are tremendous." (www.sciencelink.com).

One major source of DNA is the blood taken from newborns to check for genetic diseases. Since the mid 1960s the blood has been dried on "Guthrie cards" and stored in state laboratories. Some keep the cards for a few weeks, others up to 25 years. DNA samples are also taken from military recruits. According to the Coast Guard, samples are stored for 50 years, and DNA tests are conducted only to identify a soldier's body. A third major source is the FBI's Combined DNA Indexing System (CODIS), which compiles DNA profiles of people convicted of felonies and from evidence collected at crime scenes.

In 1998, the National Commission on the Future of DNA Evidence was commissioned to explore the use of DNA in the criminal justice system. At a 1999 commission meeting, Dr. Phillip Reilly, former director of the Shriver Center for Mental Retardation and now CEO of Interleukin Genetics said, "We have actually arrived at universal DNA databanking. It's just no one's talking about it." But although millions of samples are being gathered, the databanks aren't linked, the samples aren't contained in a single database, and no one's looking for DNA in them. They're simply bits of tissue on laboratory shelves. That's one reason the samples don't threaten personal privacy, said Patricia Roche, Assistant Professor of Health Law at Boston University and co-author of the 1995 *Genetic Privacy Act*. "Stuff is being banked," she said. "Whether it's being banked with the intent to look at the DNA in it is a different question. Until somebody tries to take some real content information out of it, there's no privacy issue triggered."(www.ornl.gov.com).

Law enforcement agencies have used DNA fingerprinting to create databases of genetic profiles of convicted criminals. One such database, the National Database Indexing System (NDIS), is maintained by law enforcement agencies in the United States. The NDIS is part of a national database of DNA profiles called the "Combined DNA Indexing System" (CODIS). Such databases allow law enforcement laboratories to compare profiles of convicted

offenders with samples from crime scenes. DNA evidence was first used in 1986 in Pennsylvania. Since then it has been used and widely accepted in both criminal and civil cases.

According to the FBI, in approximately 200,000 cases that have been worked using DNA fingerprinting technology in the FBI laboratories, twenty-five percent of the cases excluded the suspects from being responsible for the crimes. New technology called STRs (short tandem repeats) enables small samples of DNA to be copied millions of times with little degradation, with samples of fragments that can be used. Old technology like RFLP (restriction fragment length polymorphism) had a success rate of as little as five percent, whereas STR's were nearly one hundred percent most of the time depending on where the DNA fragments was obtained. The use of CODIS (combined DNA indexing system) was developed by the Federal Bureau of Investigation. The CODIS system is a partnership between the Federal Government and state and local governments, and the Department of Justice. The CODIS system contains two profile file systems. The first file contains DNA profiles from convicted offenders from state and local jurisdictions, and a second file contains the forensic DNA evidence from a crime scene that has not been matched to any offender. Through the use of CODIS there is an attempt to link cases from the offender file to the forensic file, or to link one unsolved case with another in hopes of putting investigations together on the same track to identify the same individual. CODIS can be found in 114 laboratories across the United States and in 43 states. As of 1999, the number of DNA samples collected was over 700,000, but only half were analyzed using CODIS technology due to lack of personnel and resources. The CODIS system is being used for current and old cases that are pending. The used of the system will increase as legislation and funding are modified. The CODIS technology also contains a third file which holds the DNA information for missing persons. The CODIS system is also being implemented internationally as there are more countries requesting the software.

Privacy and Ethics

When technology like CODIS is used, the question of privacy arises by the opponents of keeping personal genetic information where it may be used improperly. What would prevent these laboratories from conducting unauthorized genetic research?

The defense is that these laboratories have plenty of work to do just keeping up with the case work, and are not about to go around trying to do genetic research. They also claim that the system is secure from tampering from outside sources. Security is another question that is

addressed, especially considering the recent problems of computer hackers breaking into systems that were considered to be "secured systems." The laboratories involved are considered the best regulated data banks in the country. The claim is that these are the same individuals who worry about insurance companies and employers asking, as a matter of practice, for blood samples or urine samples. They claim these companies are already capable of ascertaining this information anyway. (www.ornl.gov).

Frequently asked questions about DNA privacy would be: Do you need personal information? How is my personal information used? Will my personal information be disclosed? Here is a typical privacy statement: We at DNA Offers take the issue of safeguarding your online privacy seriously. In this statement you will be notified of: What personally identifiable information of yours is collected; What organizations are collecting the information; How the information will be used; With whom the information will be shared; What choices are available regarding collection, use, and distribution of the information? What kind of security procedures are in place to protect the loss, misuse, or alteration of information under the companies control; and how can you correct any inaccuracies in the information? and, how is personal information disclosed?

Another concern about database files and information is that when an individual is found to be innocent, the DNA sample will still be on file. There is also the concern about the potential for abuse of an individual's file. The Justice Department dismisses the concerns stressing that the privacy issues are fully vetted as people expand DNA testing. Again there is another concern with a systems ability to be hacked, or not. Worst case concerns are that the individuals personal DNA information could be used against them if insurance companies, employers, schools, adoption agencies, and many other organizations could gain access to these files on a "need to know" basis or "in the public interest." Imagine then that an individual could be turned down for jobs, insurance, adoption, healthcare, and other services and benefits on the basis of information contained in their DNA profile that could include a genetic disease, heritage, or another person's subjective idea of a "genetic flaw."

You can stop imagining this scenario; Canada has been collecting DNA and has the worlds most sophisticated DNA database. This is capable of automatically identifying a person through analysis of small amounts of blood, semen or skin cells. DNA as forensic evidence was first used in Canada in 1988, and since then laws have been passed requiring DNA samples of all citizens including newborn babies. The guess would be that most, if not all, Canadians are in the database,

with many other countries willing to follow Canada's lead. Canada's Privacy Commissioner, Bruce Phillips warns of the danger this database poses: "Unique personal identifiers and powerful technologies may appear to solve immediate administrative problems, but they pose long term threats to individual privacy, a fundamental value in a democratic society."

Genetics Privacy and Legislation

I. Federal Policy History

No federal legislation has been passed relating to genetic discrimination in individual insurance coverage or to genetic discrimination in the workplace.

Several bills were introduced during the last decade. Some of these bills attempted to amend existing civil rights and labor laws, while others stood alone. The primary public concerns are that (1) insurers will use genetic information to deny, limit, or cancel insurance policies or (2) employers will use genetic information against existing workers or to screen potential employees, because DNA samples will be used for purposes other than those for which they were gathered. (www.ornl.gov/hgmis/elsi/legislat.html).

II Why Legislation is Needed Now

(1) Based on genetic information, employers may try to avoid hiring workers they believe are likely to take sick leave, resign, or retire early for health reasons (creating extra costs in recruiting and training new staff), file for workers' compensation, or use healthcare benefits excessively.

(2) Some employers may seek to use genetic tests to discriminate against workers, even those who do not and may never show signs of disease because the employers fear the cost consequences.

(3) The economic incentive to discriminate based on genetic information is likely to increase as genetic research advances and the costs of genetic testing decrease.

(4) Genetic predisposition or conditions can lead to workplace discrimination, even in cases where workers are healthy and unlikely to develop disease or where the genetic condition has no effect on the ability to perform work.

(5) Given the substantial gaps in state and federal protections against employment discrimination based on genetic information, comprehensive federal legislation is needed to ensure that advances in

genetic technology and research are used to address the health needs of the nation, and are not used to deny individuals employment opportunities and benefits. Federal legislation would establish minimum protections that could be supplemented by state laws.

(6) Insurers can still use genetic information in the individual market in decisions about coverage, enrollment, and premiums.

(7) Insurers can still require individuals to take genetic tests.

(8) Individuals are not protected from the disclosure of genetic information to insurers, plan sponsors (employers), and medical information bureaus without their consent.

(9) Penalties in HIPA (Health Insurance Portability and Accountability) for discrimination and disclosure violations should be strengthened in order to ensure individuals of the protections afforded by the legislation. (www.ornl.gov/hgmis/elsi/legislat.html).

III. Executive Order Protecting Federal Employees

On February 8, 2000, U.S. President Clinton signed an *executive order* prohibiting every federal department and agency from using genetic information in any hiring or promotion action. This executive order, endorsed by the American Medical Association, the American College of Medical Genetics, the National Society of Genetic Counselors, and the Genetic alliance:

Prohibits federal employees from requiring or requesting genetic tests as a condition of being hired or receiving benefits. Employers cannot request or require employees to undergo genetic tests in order to evaluate an employee's ability to perform his or her job.

Prohibits federal employers from using protected genetic information to classify employees in a manner that deprives them of advancement opportunities. Employers cannot deny employees promotions or overseas posts because of genetic predisposition for certain illnesses.

Prohibits strong privacy protections for any genetic information used for medical treatment and research. Under the EO, obtaining or disclosing genetic information about employees or potential employees is prohibited except when it is necessary to provide medical treatment to employees, ensure workplace health and safety, or provide occupational and health researchers access to data. In every case where genetic information about employees is obtained, it will be subject to all federal and state privacy protections. (www.ornl.gov/hgmis/elsi/legislat.html).

IV Genetic Nondiscrimination Bills from the 106th Congress 1999-2000

H.R.293,Genetic Information Health Insurance Nondiscrimination Act of 1999 Sponsor: Rep John E. Sweeney (introduced 01/06/99). A bill to amend the Public Health Service Act and the Employee Retirement Income Security Act of 1974 to prohibit health insurers and group health plans from discriminating against individuals on the basis of genetic information.

H.R. 306,Genetic Information Nondiscrimination in Health Insurance Act of 1999 Sponsor: Rep Louise McIntosh Slaughter (introduced 01/06/99). A bill to prohibit discrimination against individuals and their family members on the basis of genetic information or a request for genetic services.

S.300, Patients Bill of Rights plus Act

Sponsor: Sen Trent Lott (introduced 01/22/99). A bill to improve access and choice of patients to quality, affordable health care. Includes section on genetic information nondiscrimination in health insurance.

S.326,Patients Bill of Rights Act

Sponsor: Sen James M. Jeffords (introduced 01/28/99). A bill to improve the access and choice of patients to quality, affordable health care. Includes section on genetic-information nondiscrimination in health insurance. (www.ornl.gov/hgmis/elsi/legislat.html).

V. State Policy History

States have a patchwork of genetic-information nondiscrimination laws, none being comprehensive. Existing state laws differ in coverage, protections afforded, and enforcements schemes. Some of the first state laws enacted to address this issue prohibited discrimination against individuals with specific genetic traits or disorders.

Other state laws regulate both the use of genetic testing in employment decisions and the disclosure of genetic test results. These state laws generally prohibit employers from requiring workers and applicants to undergo genetic testing.

Problems-Examples

Burlington Northern Santa Fe Railroad settled out of court with two unions representing railroad employees. The unions alleged that the company coerced employees into providing blood samples that would

be used for genetic screening. An attorney for the unions said that the railroad has agreed to destroy the test results and to help get federal legislation passed to prevent genetic testing by employers in the future. The railroad agreed to destroy blood samples from the workers who were tested and delete the results from the employees' records. (www.wired.com).

Icelanders are accusing their government of taking huge payments from the company Decode Genetics, which was licensed to create a genetic database of the country's entire population. Although trading money for influence is nothing new, critics are reacting harshly, at least partly because the information involved is so sensitive. The matter is the government allegedly accepting money from Decode Genetics, a biotech firm, even as it was trying to pass a genetics bill. The genetic database is a sweeping project approved by the Icelandic Parliament through the Icelandic Health Sector Database Act in 1998. In January, 1998, parliament granted Decode an exclusive license to the database for 12 years. Decode targeted the 275,000 Icelanders because they are so homogenous, meaning that genetic anomalies will stand out much more clearly than in a melting pot like the United States. Researchers believe that creating a massive genetic database could lead to the discovery of disease patterns and new drugs. But Decode's database has been widely criticized by several groups including the World Medical Association and the Icelandic Psychiatric Human Rights Group. A major concern is privacy. The database will contain genetic information of practically all Icelanders. In addition, citizens are assumed to agree to participate unless they opt out. To date, 17,240 have done so. Also, the twelve year exclusive license to own Iceland's genetic information and ability to sell any discovery the research yields strikes some detractors as a monopoly. (www.wired.com).

Implementation

#1. Building a model of a DNA molecule.

Models will be based on the basic model of Watson and Crick.

Students may use any materials they feel appropriate to design and build. The bases must be equal and must be paired correctly, and the steps must follow the correct pattern. This project will allow students to better understand the basic DNA molecule.

#2. Concept map.

Students will develop a concept map on the step-by-step process of "gel electrophoresis" as developed by Alec Jeffery. Concept maps will help students better understand the process of "gel electrophoresis."

#3. Students will write a short essay on the works of Rosalind Franklin with emphasis on her work in x-ray crystallography. This work will be computer generated. Information will be gathered through research of published materials and the internet (library). This work will help the students when they study the work of James Watson and Francis Crick.

#4. Students will write a short essay on the works of James Watson and Francis Crick and their discovery and design of the DNA molecule and the double-helix shape. This work will be computer generated. Information will be gathered through research of published materials and the internet (library). This work will help students better understand what all of the news is about when discussions on genetics are presented.

#5. Ethics.

Student will be provided case studies in the use of genetic database systems. Knowing how DNA is extracted, what type of information can be found, and what type of scientific discoveries might come from this students will write their opinions and give support for or against having their genetic information stored in a database system. The privacy issues will be discussed in this project. Students will use a previously determined list of internet sites for current information.

#6. Genetic History.

Students will attempt to develop their own genetic history by interviewing their parents, grandparents, and any close relatives. Students will be looking for traits such as eye color, hair color, skin pigmentation, height, diseases, and any other information.

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www.wired.com

www.worldbookonline.com

www.ornl.gov (truth in justice)

www.nhgri.nih.gov (the genome project)